

Hastings Center calls on health care professionals and organizations to meet standards for good care near the end of life

May 7 2013

People with chronic or life-threatening illnesses often experience problems with their care, including confusion and conflict over how to make good decisions, poor communication with care providers, inadequate pain and symptom relief, and treatments with little or no benefit. Poor care decreases patients' quality of life, increases family stress, and adds cost but not value to health care, often with heartbreaking financial consequences for families. A new set of consensus guidelines produced by The Hastings Center can help health care professionals improve care near the end of life. The guidelines clarify what is ethically and legally permissible in the United States regarding the use of life-sustaining technologies, provide in-depth guidance on talking with patients and surrogates, and offer recommendations about how to improve the delivery of care.

[The Hastings Center Guidelines for Decisions on Life-Sustaining Treatment and Care Near the End of Life](#), just released by Oxford University Press, updates and significantly expands the Center's groundbreaking comprehensive ethics guidelines first published in 1987. The original edition was foundational in shaping the ethical and legal framework for medical decision-making in the U.S. It was cited in the U.S. Supreme Court's 1990 decision in the case of Nancy Beth Cruzan, which established the Constitutional right of patients to refuse life-sustaining medical treatments and affirmed the authority of surrogate decision-makers for patients without decision-making capacity. The

original edition has also been influential internationally.

The new book synthesizes the past 26 years of research and innovation in quality improvement, patient safety, and palliative care, with insights from more than 60 experts in medicine, law, nursing, and other disciplines, as well as from the disability community and patient advocates. Two important new features include guidance on making decisions for seriously ill or dying children and a discussion of the views of people with disabilities who face decisions about life-sustaining treatment.

"This new resource comes at a time of many challenges in our [health care](#) system," says [Mildred Z. Solomon](#), president of The Hastings Center and a member of the Guidelines project working group. "As the population ages, more people are living with chronic diseases. Advances in medicine have created both benefits and burdens, including problems of quality, safety, access, and cost. We need to help patients and families better navigate their choices, and physicians and health care leaders must build systems of care that are wiser and more compassionate. Guidelines helps meet these challenges."

The authors of the new Guidelines are Nancy Berlinger, a research scholar at The Hastings Center who directed the Hastings Center project that produced the new publication; Bruce Jennings, a Hastings Center Fellow, director of bioethics at the Center for Humans and Nature, and a co-author of the first edition of Guidelines; and Susan M. Wolf, also a Hastings Center Fellow, who is McKnight Presidential Professor of Law, Medicine & Public Policy at the University of Minnesota and who directed the first Guidelines project and was principal author of the first edition.

"We wrote the new Guidelines for every health care professional responsible for the care of a patient facing decisions about life-

sustaining treatment or approaching the end of life," says Berlinger. "The book is designed for practical use in hospitals, nursing homes, community health settings, or anywhere that professionals, patients, and loved ones need to discuss a patient's values and preferences concerning different options for treatment and care. The guidelines offer a reliable framework for these discussions, and for education, policy-making, and redesign of care. They also encourage health care leaders and administrators to support better outcomes for patients by building more effective forms of care delivery and integrating care near the end of life into organizational safety and improvement initiatives."

The book separates fact from fiction, clarifying misperceptions that can lead to problems or conflict. For example, readers will learn why a physician's offer or a family's request to "do everything" for a patient is not an effective way to respect a patient's rights or to ensure that a patient receives good care. The publication also explains a patient's right to refuse life-sustaining treatment, with a clear description of how treatment refusal differs from physician-assisted suicide. It describes what all patients should expect, including pain and [symptom relief](#) and respect for their preferences in all treatment and care plans.

It offers guidance on how to avoid common communication problems when discussing different medical conditions. A section on brain injuries, for example, summarizes research findings on neurological states and their implications for prognosis and making decisions about care. How [surrogates](#), families, and even clinicians understand neurological states "may be influenced by how terms such as 'coma' or 'brain dead' are used in everyday speech, by media coverage of high-profile cases, or by fictional portrayals of film or television characters who wake up from 'comas' after years or decades," the authors write, adding that [health care professionals](#) "should anticipate the need to define terms and correct misperceptions" when discussing these decisions.

The book gives extensive practical [guidance](#) on a range of topics, including advance care planning and advance directives, determining decision-making capacity, and all aspects of surrogate decision-making for adults and children. It outlines strategies to help patients, families, and professionals work together to resolve conflicts. It explains the cultural, psychological, and social factors, including religion and spirituality, that may shape people's values or influence how they make medical decisions, insights that can help health care professionals provide the most appropriate and respectful care.

The new edition of the Guidelines acknowledges cost as an ethical concern in health care. "The ethical goal of treating all patients equitably requires health care institutions to grapple with the moral as well as the fiscal dimensions of resource allocation and health care cost," the authors write. "Professionals need opportunities to discuss these difficult issues in an open and factually well-informed way." The book includes a guide for hospitals and other institutions, with six strategies to encourage productive discussions that can support the development and use of a transparent policy.

Describing the Guidelines, Kathleen M. Foley, M.D., a pioneer in palliative care and the Chair of The Society of Memorial Sloan-Kettering Cancer Center, writes, "It is the sourcebook for how the ethics of life-sustaining treatment and care at the end of life should be taught, institutionalized, and translated into clinical teaching and practice."

Provided by The Hastings Center

Citation: Hastings Center calls on health care professionals and organizations to meet standards for good care near the end of lif (2013, May 7) retrieved 27 April 2024 from <https://medicalxpress.com/news/2013-05-hastings-center-health-professionals-standards.html>

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